



Heriot-Watt University  
Research Gateway

## The 'New Dementia': Widening Choices for our Future Support

### **Citation for published version:**

Wilkinson, H, Taylor, L, Marshall, M, Christie, J, Nioi, A, Hamilton-Pryde, AM, Payne, SR, Hare, P, McKillop, J, Houston, A, Ramsay, A, Noone, A & Ramsay, F 2017, The 'New Dementia': Widening Choices for our Future Support. Scottish Universities Insight Institute.

### **Link:**

[Link to publication record in Heriot-Watt Research Portal](#)

### **Document Version:**

Publisher's PDF, also known as Version of record

### **General rights**

Copyright for the publications made accessible via Heriot-Watt Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

### **Take down policy**

Heriot-Watt University has made every reasonable effort to ensure that the content in Heriot-Watt Research Portal complies with UK legislation. If you believe that the public display of this file breaches copyright please contact [open.access@hw.ac.uk](mailto:open.access@hw.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

# The 'New Dementia': Widening Choices for our Future Support

A project of the Scottish Universities Insight Institute

September 2017



A briefing paper written by and with people affected by dementia in Scotland:  
Agnes Houston, Dr. James McKillop, Archie Noone,  
Anne Ramsay, Frank Ramsay

# Contents

Section	Title	Page
1	Accessible summary	3
2	Introduction	4
3	Our knowledge exchange aims	10
4	Hopes, fears and reflections	15
5	So what would we want?	23
6	Next steps	25
Appendix 1	The project team	28
Appendix 2	About the contributors	28

## Section1: Accessible summary

This briefing paper is written by and with a group of people with dementia in Scotland.

It aims to start a new conversation about the choices open to people with dementia who may no longer be able to live in their own homes.

Discussion was stimulated by presentations on small group models in Canada, Japan and Australia.

The hopes, fears and reflections of the group focused on:

- Making decisions – and needing support to do so
- Choice
- Informality
- Freedom and risk
- Physical space and opportunities for quiet
- Who schemes are for
- End-of-life care

This project raises questions and challenges that we would like those in a position of influence to consider. These include:

How can choice and decision-making be supported?

How can we understand better the priorities and aspirations of people living with dementia, and also of their families?

How can planning for the future help us to meet these aspirations?

As one of the group put it: *“These examples from overseas help to show what we could aspire to in this country. But would we accept the cost?”*

... and as another responded: *“But can we afford not to change things? The cost to the ‘human element’ could be more in the long run if we don’t. If it’s not working, let’s look through a different prism. We need choice.”*

## Section 2: Introduction



Agnes Houston

### 2.1 The project

This briefing paper is the product of a small project funded by SUII (the Scottish Universities Insight Institute). The partners were:

- People living with dementia in Scotland (Agnes Houston MBE, Dr. James McKillop MBE, Archie Noone, Anne Ramsay, Frank Ramsay)
- Dementia Centre HammondCare (Dr. Julie Christie, Prof. Mary Marshall)
- Innovations in Dementia CIC (Philly Hare)
- The University of Edinburgh (Edinburgh Centre for Research on the Experience of Dementia) (Prof. Heather Wilkinson, Dr. Liz Taylor)
- Heriot-Watt University (Health and Wellbeing in the Built Environment group) (Dr. Amanda Nioi, Alison Hamilton-Pryde, Dr. Sarah Payne)

This project addresses an emerging and substantial issue facing Scotland and beyond. This affects people with dementia who, mainly due to policy developments such as Scotland's National Dementia Strategies, have received an early diagnosis of dementia, and have now been living with

dementia for five plus years. Some of these people have coined the phrase ‘the New Dementia’, because their experience defies dominant medical understandings of the middle stage of dementia. People in this group continue to lead active lives, and, while they do need support and may not be able to stay at home much longer, are not ready to move to institutional-like care homes.

The work took place between April and September 2017. It aimed to support people with dementia, policy makers and other stakeholders in Scotland to learn from other countries, and each other, about alternative housing-with-care/care home models, through co-produced films, workshops and this briefing paper.

The Dementia Centre, HammondCare has an academic partnership with ECRED at the University of Edinburgh. Combining research, education and practical experience, the Dementia Centre works to empower everyone to take action to improve the quality of life for and with people living with dementia. This project marks a new interdisciplinary collaboration between research centres at University of Edinburgh and Heriot-Watt University. This work is innovative in that it addresses an emerging situation, works with people with dementia to find solutions, and seeks to learn from people with dementia in other countries where alternative housing-with-care/care home models are further advanced.

The aim of this project is twofold;

- to investigate alternative housing-with-care/care home models from overseas through experiential approaches, which enhance the meaningful involvement of people with dementia
- to facilitate cross-sector discussions on lessons to be taken from these models and applied to the Scottish context.

## **2.2 Background**

In recent years there have been many concerns about the quality of residential care services for older people<sup>1</sup> and the current and future funding of long-term care; and a growing recognition of the need to radically shift attitudes towards,

---

<sup>1</sup> Parliamentary and Health Services Ombudsman, 2011; J. Cornwell, King's Fund, 2012

and understanding of, the huge *diversity* of older people in our society today rather than focusing on *numbers* alone.

Alternative accommodation approaches to support people with dementia have recently emerged - particularly overseas. Based on an extensive review of research<sup>2</sup>, the 'Housing with Care' guide outlines the design, facilities, care and support that best enable older people with dementia to live independently. It points to the benefits of a lifestyle that offers the dignity and sense of wellbeing that older people seek, based on three key principles: Independence, Empowerment and Accessibility.

The policy drive to ensure earlier diagnosis with dementia has now created a more nuanced situation in relation to housing-with-care/care homes. There is an emerging group of people living with dementia at home for five plus years. They continue to function well but are getting to the point where they need support and may not be able to stay in their own homes. However current models do not meet their aspirations for continued independence and active citizenship.

A JRF report<sup>3</sup> found that older people with high support needs want greater choice and control over their lives and a wider range of options. This study identified the benefits and potential of options based on mutuality (people supporting each other) and/or reciprocity (people contributing to individual and group wellbeing), and found that:

- Adapting ways of working from other countries, e.g. Denmark, could stimulate further development in the UK
- Communicating the range and benefits of different models to older people, their families, the wider public and frontline staff will raise awareness, increase take up, and drive local developments.

The aim of our project addresses both of these benefits, by examining alternative models from other countries, communicating these approaches to all the key stakeholders, including people with dementia, and together, and developing a brief which identifies ways Scotland can advance and take on the positive, applicable aspects of these models.

---

<sup>2</sup> Housing and Dementia Research Consortium (2009)

<sup>3</sup> 'Widening choices for older people with high support needs' (Bowers et al 2013)

It challenges current models of accommodation for people with dementia in Scotland, uses learning from Canada, Japan and Australia to build upon existing work, and through policy workshops, hopes to influence the future direction of developments.

Building on the coproduction model of working in ECRED, and drawing on theories of citizenship<sup>4</sup>, the project also challenges a traditional academic research approach by ensuring that the views and experiences of people with dementia are central in the sharing and development of knowledge.

## **2.3 Scotland policy context**

This project builds on existing Scottish resources and evidence from government reports<sup>5</sup>, and previous SUIL recommendations<sup>6</sup>, to support people with dementia, policy makers and stakeholders in Scotland to learn about housing-with-care/care home models.

Dementia is recognised as a key social, policy, and economic challenge, not least in terms of the forms of housing, support and care this growing population require. A key commitment of Scotland's National Dementia Strategies (2010, 2013-2016) was to improve rates of early diagnosis of dementia so people could access support earlier. Another Scottish Government commitment of the Dementia Strategy and the Strategy for Housing for Scotland's Older People (2012-2021) is to develop safe and supportive environments that promote independence and quality of life for people with dementia.

The project is very timely in that it reflects many of the key outcomes of Scotland's National Dementia Strategy 2017-2020<sup>7</sup>:

- more people have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning

---

<sup>4</sup> Bartlett & O'Connor, 2010

<sup>5</sup> e.g. Mullan & Woolrych, 2016 Designing Places for an Ageing Population, The Scottish Government

<sup>6</sup> e.g. 'The Memory Friendly Neighbourhood Programme'

<sup>7</sup> <http://www.gov.scot/Resource/0052/00521773.pdf>



- more people get earlier access to good quality, person-centred postdiagnostic support in a way that meets their needs and circumstances
- more people with dementia are enabled to live well and safely at home or in a homely setting for as long as they and their family wish
- more people get timely access to good quality palliative and end of life care
- during the process of diagnosis and through all parts of the care journey, the critical input of family carers is encouraged and facilitated, and carers' own needs are recognised and addressed
- people with dementia's right to good quality, dignified, safe and therapeutic treatment, care and support is recognised and facilitated equally in all care settings – at home, in care homes or in acute or specialist NHS facilities
- there are more dementia-friendly and dementia-enabled communities, organisations, institutions and initiatives.

The Scottish Government defines a care home as a place where people can live in a homely setting and have their needs met by trained staff. Care homes are required to be registered and inspected by the Care Inspectorate and may be owned and run by local authorities, private individuals, companies and the voluntary sector. There is a wide range of care homes, some specialising in specific types of care such as dementia. Care homes which are registered with the Care Inspectorate to provide nursing care have trained nurses.

Care Information Scotland<sup>8</sup>, launched in 2010 by the Scottish Government and managed by NHS 24, offers a single point of contact for people seeking care information in Scotland. Care Information Scotland state that: *“The social care department can help you to find a care home even if you plan to fund your own place. You'll get a list of suitable care homes and help to arrange trial visits. You should have a choice of different care homes, but the following can limit your options; the availability of suitable accommodation in relation to your assessed needs; whether the cost to the local council (if it's paying towards your care) is more than it usually pays; whether accommodation is available and if the care home is willing to provide accommodation.”*

However, in Scotland, for the emerging 'New Dementia' group who have been living longer at home and stayed active in their community, there remains a

---

<sup>8</sup> <http://www.careinfoscotland.co.uk/>

gap in the provision of housing-with-care models that continue this independence and quality of life. The innovative small-scale approaches seen in the 1990's have not progressed, and most of those who can no longer live at home have little choice but to enter a setting they see as institutional, in which they may quickly become passive recipients of care.

## 2.4 Public perceptions of care homes

The small group of people affected by dementia involved in this project (see Section 3) identified a number of public perceptions about care home provision which, in their view, influence thinking and decision-making. The main perceptions are that...

- **Costs** are a big barrier, and they are going up – yet no one knows how long they will live. Families often have to 'top up', so *"the government is giving you money towards your care, not for it."* There are additional costs for 'extras' such as toiletries, treatments etc. Financial issues really restrict the individual's options. There may also be a [social] division between those who fund themselves and those who are supported by the State
- **Care home staff** are underpaid and *"if you pay peanuts, you get monkeys."* There is also a high turnover, putting more pressure on the more experienced staff who stay.
- **Families** suffer from guilt at having to make big decisions without adequate support and information, and potentially having to pay large top-ups.
- **Knowledge** of care homes usually comes from chats with work colleagues/friends or the media. It is not necessarily evidence-based. The bad press about closures and the occasional scandals cause a lot of anxiety.
- **Politicians** are not trusted to change things: *"Parliament are only interested in the time they are in power, not in the long-term."*
- **Advice** varies as to whether it is better to move or stay put after diagnosis – and at what stage to move, if ever.

## Section 3: Our knowledge exchange aims



James McKillop

This knowledge exchange project focuses on two key questions:

Do housing-with-care/care homes in Scotland reflect the needs and aspirations of people living with dementia today and in the future?

If not, what would it take to achieve this?

This project focuses on this issue of choice and availability of options. People living with dementia in Scotland are anxious about being 'put' into care settings that are regimented and boring, in which they feel they may lose their identity and have their choices restricted. So they are looking for alternatives.

Through a process of co-production, we worked with people with dementia to bring their learning from Japan, Canada and Australia directly to those who

have the power to influence change in policy and practice in relation to the provision of alternative housing-with-care models for people with dementia living in Scotland. This form of experiential and international knowledge from people with dementia themselves has been a core contribution to the workshops and vital for the success of the project objectives.

On Friday 14 July 2017, several people who are affected by dementia (four living with dementia, plus one carer) met at the Festival Theatre in Edinburgh to discuss their hopes, fears and wishes about their futures - especially if that were to involve a move to some kind of supportive accommodation/care home.

As part of the facilitated discussion, the participants were shown brief presentations about options available overseas. Participants shared knowledge of small group living models of care from Australia and Japan, and of a retirement village model from Canada.

Japan, with over 5 million people living with dementia, has developed innovative accommodation models which enable people with dementia to live as active citizens and remain connected within their communities. Japan now has over 12,000 state-funded dementia group homes.



Japan group home

Schlegel Villages offer residential living that combines quality long-term care with retirement villages across Ontario, Canada. They cite their defining features as: physical design, investment in people, integration with the larger community, and innovation. The design of the space creates a 'village' feel, with recognisable places such as Town Square and Main Street. The communities also provide a Town Hall, café and Community Centre. Integration with the larger surrounding communities is essential to the ethos of Schlegel Villages<sup>9</sup>.



A Schlegel Village, Canada

HammondCare is an independent Christian charity specialising in dementia and the care of older people, palliative care and rehabilitation. They are one of Australia's most innovative health and care providers, delivering hospital and residential care and community services. They also host the Dementia Centre and have a commitment to dementia care and research.<sup>10</sup>

The presentations included:

- a short film, 'Learning from Japan'<sup>11</sup>, put together by Liz Taylor and Philly Hare, following a study tour of group homes in Japan earlier in 2017. James McKillop also contributed from his previous visits to Japan.

<sup>9</sup> <http://schlegelvillages.com/about>

<sup>10</sup> <http://www.hammond.com.au/>

<sup>11</sup> <https://vimeo.com/224291181/5630ad08cb>



- a presentation by Prof. Mary Marshall, and a short film, 'Maria's story'<sup>12</sup>, about HammondCare 'cottages' in Australia. Agnes Houston also contributed from her visit to Australia in 2016.
- a presentation by Agnes Houston about her recent visit to Schlegel villages in Canada, using her Winston Churchill Travelling Fellowship bursary<sup>13</sup>.



HammondCare cottages

These were presented not necessarily as models to be admired and copied, but to stimulate discussion.

This briefing paper has been co-produced with those participants through the process of two workshops. It aims to share the reflections of the group with key influencers in Scotland.

Attendees from the workshops, key policy makers, and other stakeholders in Scotland (e.g. from design, care and voluntary sectors) were invited to review the briefing paper and discuss future directions for Scotland at an event held on 20 September 2017.

<sup>12</sup> <https://www.youtube.com/watch?v=Rfo2RIrxnog>

<sup>13</sup> 'Think Dementia, Think Sensory' Houston, A 2017

We hope that this will lead to further dialogue with people with dementia themselves, and potentially to developments in the choices offered to people with dementia who may at some point no longer be able to live in their own homes.

## Section 4: Hopes, fears and reflections



Anne and Frank Ramsay

In this section we outline the views of the group as expressed in the two workshops (July and August 2017).

### 4.1 Making decisions – and needing support to do so

The group was very aware of the momentous nature of decision-making about future options. But they felt unsupported in this process, even though some had been living with dementia - and therefore known to the services - for many years. Here are some of their comments:

*“If and when to move? Should I downsize? Will it be the right move for all time?”*

*“People advise you not to move – the literature says not to move at the beginning. You have to follow the experts. I wanted to move when I got my diagnosis, but the the consultant and my daughter said the literature says don't. But now, 11 years on, the house is not safe for me, I fall all the time. But*



*it would be more difficult to move now, as I won't be able to recognise my new environment. If I had moved at the start I would have become more familiar with the local environment and the neighbours... So if you don't move, that can be irreversible too."*

*"But if you are alone – you have to think about the future."*

*"You need information about your options if you own your house."*

*"Not being able to manage one's own garden is a big reason for thinking about moving."*

*"Because we have dementia, we don't get [given] the same knowledge and information. Other disciplines – e.g. housing officers – don't know how to communicate with a person with dementia, or what information they can handle."*

*"We can't afford to move, as we can't get a mortgage because we're retired. But living where I do is stressful and I'm worried about having a heart attack (particularly as it's noisy outside, and school visitors regularly block my driveway)."*

*"Moving is very costly...but we might make the wrong move."*

*"A move is irreversible – you can't backtrack on it."*

The group felt that discussion about future support should be an integral part of post diagnostic support (PDS) for all. However, they were skeptical about the current situation:

*"We hope diagnosis is done better now. Mine took 5 minutes. I didn't know what to do so I stayed in the house for 3 weeks. That was 6 years ago, so it might have changed now."*

*"There is post diagnostic support (PDS) now – but 400 people are waiting for it. The Government says only 40% are getting it."*

*“PDS is only for the newly diagnosed! There is no support for the ‘walking dead’ [those diagnosed a while ago]. I feel bitter, and abandoned by Scotland.”*

*“We don’t know our choices. We are told to think of today. There is no planning for tomorrow.”*

*“I haven’t been given help to adapt my home so I can stay there longer (even small things like brighter light bulbs can make a big difference.)”*

*“We need help with planning end-of-life – that needs skills.”*

*“Decisions are often made in a crisis. There may not be any choice at all in an emergency. The place chosen may be far away and mean visits are expensive.”*

Prof. Mary Marshall pointed out that there *are already* several small group-living housing projects in Scotland, and several care homes run on a small group living model, as well as five retirement villages. However, it seems that many may not know about them – certainly none of this group was aware.

## **4.2 Choice**

Even if they were to be offered help in making their decisions, overall the group felt there is very little choice for them in terms of their futures – and that the available options, if taken up, would almost inevitably curtail their freedom and autonomy:

*“There is little choice. I’m hoping for a good future – but [knowing] what is in my area, it would be a loss of freedom, a loss of connection to outside, a loss of choice... a loss of Me.”*

*“We are told we have to manage (i.e. lower) our expectations. But you need to create new dreams and hopes!”*

*“There is no choice at the moment, except for take it or leave it.”*

*“It shouldn't be a case of... this is what we will provide for you.”*

### **4.3 Informality**

Informality was perhaps the key feature to come out of the presentations the group was shown – and something they found very attractive:

*“It's friendlier than in the UK – a family atmosphere.”*

*“No chairs in a circle.”*

*“There are children around.”*

*“Laughter!”*

*“The feeling of being in it together. Not [what I've come across]... them and us.”*

*[about the HammondCare film] “It was definitely different to Britain. They were kinder.”*

*“Pets! Did the dog live in the home?”*

The films also stimulated discussion about uniform – in the Japan group homes, staff don't wear uniforms, in the Schlegel villages, they wear polo shirts with a logo.

*“It's brilliant to have none.”*

*“Either no uniform or casual uniform - but I would want name badges.”*

However, the group agreed that nurses at least should be in uniform, so they can be easily identified.

#### 4.4 Freedom and risk

The level to which risk should be negotiated and managed was of great importance to those in the group. They pointed out that too much risk-aversion brings its own risks.

*“The feeling of being safe is very important.”*

*“I would hope for support and technology – something to help us not get lost.”*

*“You’re free to make a cup of tea [in the group home/cottage model]. We are more risk-averse here... in some places in the UK, you can’t get up to make a cup of tea.”*

*“There’s freedom of movement [in the group homes], no restrictions.”*

*“You can help with cleaning if you want - I could make it to my standard!”*

*“They make meals together... I think the preparation part brings them together.”*

*“I like the freedom of being a caring person.”*

*“In Canada, residents even went on holiday together.”*

*“I like the idea of the supermarket –it’s me that’s buying for me. How does it work? Do people have money to spend? Do they really buy food for the group’s meals? What if they overspend, or buy the wrong amounts, or keep coming in to the shop?”*

*“Scotland is now a very risk-averse culture.”*

*“We can’t do it here, because of health and safety. Authority (and pressure from the family?) is against us. They’re afraid of being sued.”*

## 4.5 Physical space and opportunities for quiet

The availability of physical space, both inside and outside, was of considerable importance to the group, particularly when they saw the small size of some of the Japanese group homes:

*“There is a lack of space [in Japanese group homes]. There doesn’t seem to be anywhere quiet to go to. Small is not good! Wouldn’t want to transport this feature [smallness] to Scotland.”*

*“I want a space to retire to that’s not my bedroom... to come away from the noise.”*

*“Are there any really quiet rooms?”* (Answer – the chapel and also the meditation room in Schlegel villages is non-religious and totally silent. In HammondCare cottages there is a quiet ‘parlour’.)

Outdoor space is also important. The group liked the gardens they saw in the HammondCare cottage schemes. But their perception was that, in Scottish care homes, the gardens are often locked and not accessible

*“We need outdoor space but of a manageable size – so we can sit in the sunshine in our own little patch.”*

*“It’s back to choice. If you want to go out and you can’t, that’s against your human rights.”*

*“Outdoor space can be used positively as a healing tool (instead of drugs), recognising the sensory impacts of dementia.”* Agnes Houston referred to her booklet, ‘Dementia and Sensory Challenges’<sup>14</sup>.

## 4.6 Who are small-group schemes for?

The issue of couples having to be split up if one half has to go into a care home was a real one:

---

<sup>14</sup> <http://www.lifechangestrust.org.uk/sites/default/files/Leaflet.pdf>

*“Can couples move in together?”*

*“If one dies, can the other stay – or do they have to leave (and leave their social network) because they are then blocking space for another couple?”*

There was some discussion as to whether care settings should be integrated or dementia-specific:

*“I liked that we are not creating dementia ghettos – that it’s mixed. The only time they separate people is for dementia (not diabetes, epilepsy etc).”*

However, it was also pointed out that, if settings are integrated, other residents need to understand dementia:

*“In Canada, the residents without dementia were wary of those who had it – they asked for more training.”*

#### **4.7 End-of-life care**

- *“End-of-life is a transition that can last a year or more – not just the last few days. In cancer, they give end-of-life care much sooner – we need to adapt this to suit people with dementia.”*
- [In small group homes] *“People seem to bond closely – so what happens when someone dies? I would hope there is counselling available?”*
- *“In my [dementia] group, people don’t seem to want to talk about end-of-life.”*
- *“At HammondCare, people are offered to listen to their favourite music as they are dying.”*
- *“We need skilled staff that know us. That is almost medicine for the soul.”*

There was also some discussion as to whether those care homes that have a religious connection might be ‘more caring’ [than the business model]. But some felt that a religious label or ethos (as in HammondCare) might be off-

putting to some. There followed a discussion about cultural differences to organised religion in Australia and UK. Throughout its history, HammondCare has been highly independent and the organisation works with all denominations, valuing the individuality of the people who use their services.

## Section 5: So what would we want?



Archie Noone

From the group's discussions, we identified a number of features that are important to them in any model of care. It was pointed out that these are not a 'wish-list' but a matter of *"our human rights, for example the right to a family life..."*. The six key features are:

1. An informal, family feel, a *"sense of belonging."* A non-regimented, non-institutional situation. Small units with *"a sense of love"*.
2. A positive culture, a feeling of *"helplessness-to-hopefulness"*.



3. The freedom *“to do what you want to do, when you want to do it.”*  
Reassurance of safety, but the perhaps the option to *“opt in or out of risk.”*
4. Well-trained staff (more important than the surroundings). Specifically, with skills and training in end-of-life care.
5. Quiet places to go - including access to outdoor space.
6. Flexible facilities. Different levels of care that you can move between (not have to leave). But non-segregation – not dementia-specific units. Facilities for couples (including same-sex).

It was pointed out that any ‘model’ of itself is no guarantee of an enabling regime. One of our participants had looked at a small group-living housing project, and felt it was just as regimented as a “poor quality care home”.

However, the group also felt strongly that the issue is not just about the care home itself. It starts with better post-diagnostic support, meaning a guaranteed number of sessions for all. These would provide clear information about choices – when the individual wants it.

There was also some discussion about terminology. What do they all mean (e.g. assisted living, extra care, care home)? The term ‘care home’ implies being *done to*, provided for – which is not what many want, and which goes against the principle of independent living.

## Section 6: What next?

This project raises questions and challenges that we would like those in a position of influence to consider. These include:

### 6.1 How can choice and decision-making be supported?

Can there be a single place to get information about housing models and care home models, that will meet the needs of people with dementia?

- How can people with dementia find out about the alternative models that *already* exist in Scotland
- Can these discussions be part of post-diagnostic support?
- Could there be a 'one-stop shop'?
- Could someone be appointed to go with a person with dementia to look at places, especially if they are not local. No one area has all these options available?
- Should there be particular attention given to those living alone, or with an elderly or disabled partner?
- Could there be a glossary of terms and their meanings (care home; nursing home; extra care; housing with care; retirement community; village; assisted living; cottages; group homes)?

### 6.2 How can we understand better the priorities and aspirations of people living with dementia, and also of their families?

- How can people living with dementia today be supported to use their knowledge to advocate on behalf of their future selves?
- How can people with dementia be involved in the planning of new schemes from the very start?
- How can they continue to be involved as advocates within care homes?
- How can those living in care home settings be helped to 'opt in or out of risk'?

### 6.3 How can planning for the future help us to meet these aspirations?

- Could the models we have discussed work in Scotland? *“This film [of Japan] shared a lot we could aspire to. It would fit in well to rural settings in Scotland, with their strong communities.”*
- Can providers, commissioners, planners take a closer look at other innovative alternatives to care homes, such as Shared Lives, co-housing, HomeShare etc.
- Can we look again at the *costs and benefits* of small group models of care? Is this model cheaper, or does it cost more? Can we afford *not* to innovate?
- Could young people be encouraged to spend a year working in care homes through a special high-status post-school scheme?

### 6.4 The last word

This work, with its international element, has stimulated interest in how we can be better informed about innovative care settings here in Scotland, and how we can best support people with dementia to plan for increasing care needs.

As one of the group put it:

*“These examples from overseas help to show what we could aspire to in this country. But would we accept the cost?”*

... and as another responded:

*“But can we afford not to change things? The cost to the ‘human element’ could be more in the long run if we don’t. If it’s not working, let’s look through a different prism. We need choice.”*



Group home in Japan

## **Appendix 1**

### **Project team**

People living with dementia:

Dr. James McKillop MBE; Agnes Houston MBE; Anne Ramsay; Archie Noone

Partners:

Frank Ramsay

Academics:

Prof. Heather Wilkinson and Dr. Liz Taylor (ECRED), Prof. Mary Marshall and Dr. Julie Christie (HammondCare), Dr. Amanda Nioi, Alison Hamilton-Pryde and Dr. Sarah Payne (Heriot-Watt University)

Facilitator:

Philly Hare (Innovations in Dementia)

## **Appendix 2**

### **About the contributors**

Anne Ramsay, from Edinburgh, is a mother of two, who has travelled extensively. She is still coming to terms with her fairly recent diagnosis, and dealing with things day to day, but says she has more of a social life than before her diagnosis.

Frank Ramsay is Anne's husband. He worked in telephones and TV. Together they are thinking about whether or not they should move.

Agnes Houston MBE, from Coatbridge, is an ex-nurse (A&E and the Army), a wife and mother (of Donna). Her husband also has dementia. Agnes was diagnosed 11 years ago. She is happier living day to day, but she is also a person who needs to take responsibility for future planning.

Dr James McKillop is married with four children (one in Australia). He lives in Glasgow and had his diagnosis 17 years ago.

Archie Noone, from Dundee, is a retired lecturer in anthropology and has also travelled a lot. Diagnosed 6 years ago, he now chairs SDWG. Archie says: "Dementia is the best thing that has happened to me – I have met so many people." His favourite saying is: "I have dementia... but dementia hasn't got me."